

Testimony to Appropriations Committee

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Clinton CT

Mother of Amanda Parent who is a 22 year old with I/DD and physical disabilities. She currently receives day services, 3-6 hours of respite per week and is on the residential waiting list

I am concerned that The Governor's Budget does not include allocation for day service funding.

Last June, my daughter Amanda was one of the many young adults with disabilities to graduate from her high school program. However, this was not a typical graduation time filled with celebration and discussion of what great things the future holds. Instead for my family it was a time stress and worry.

The day of her graduation was overshadowed by the fear that there will be no funding for future programming. It wasn't until 3 weeks later that she would receive programming, but full allocation was to be delayed.

This left us and many other families scrambling. I am the sole financial provider for my household and at that time held more than 1 job. My husband, who is disabled by illness, is not always able to provide the 24/7 care and stimulation she needs. As stressed as we were, the impacts on Amanda were devastating. She did not understand why everything she was used to and the routine she depended on just stopped.

This adjustment was met with many challenges, she repeatedly asked for "Aces" which was her high school program. Soon came the meltdowns, the self-injurious behaviors and aggression towards us as we were unable to maintain the routines and consistency she was used too.

Here we are 7 months later, yes funding came through and she has a program. However she is still trying to adjust and we are still in need.

I would love to stand here and say it has been a smooth transition, however it hasn't been. The transition to her adult life has been hard. We are happy she has a program, however it only meets part of her needs.

It's hard watching your child lose skills she has worked so hard to learn

It's hard watching the periods of frustration and anxiety increase.

It's hard having your spouse call you at work because he cannot physically handle the behaviors as well as the care she requires.

It's hard watching your child become so agitated and unsafe that she needed to be transported to the hospital by ambulance where it took 4 medical professionals and myself to hold her down, just to administer medications to calm her.

It's hard receiving the letter from your insurance company stating they will not pay for the hospitalization.

We have limited funds to hire help. We need help, with daily activities, personal care and respite. We need help to give her the full life she deserves.

I am left wondering, how will we manage the increasing physical and emotional responsibilities required to care for Amanda?

I know my family is not alone. This population who is unable to advocate for themselves needs to be a priority in our states. Families can't continue to work with decreasing funds and services.

As a pediatric occupational therapist, I work with families and children every day who have significant needs. I know many of my patients will need some sort of supports through DDS in the future. Planning for these individuals future's needs to happen now, not later.